

Understanding and Addressing Gaps in Access to Genetic Services

Sharon Romelczyk, MPA, Program Manager
National Genetics Education and Consumer Network



The National Genetics Education & Consumer Network (NGECN)

- Cooperative Agreement between HRSA's Genetic Services Branch & ACMG (National Coordinating Center (NCC))
- Led by Genetic Alliance
 - June 2012- May 2015
 - **New Award**: June 2015-May 2017
- Goal:
 - Collaborative network of partnerships/tools
 - Improve consumers' access to, knowledge about and quality of genetic services

What do we do?

Engagement

- Focus Groups
- Data Collection
- Program Support
- Project Advisory Groups
- Consumer Feedback

Education

- Resource Development
- Customizability
- Outreach



Engaging Individuals, Families, & Communities

Goal: Amplify the voices of consumers so that we can improve programs and systems

- RC Family Advocate Workgroups
- NGEEN Consumer Advisory Group (next slide)
- Advocates Programs (ASHG, ACMG)
- Collaboration with Family/Peer & Disease-Specific Support Groups
 - Webinars
 - Surveys/focus groups around consumer needs
 - New resource development

Engaging Across the Regions

The RC Network & NGEEN Consumer Advisory Group



Sharing Best Practices

- Meet quarterly to discuss consumer needs and lessons learned across regions
- Review consumer-focused educational tools
 - Advocacy ATLAS, DiseaseInfoSearch.org, GenesInLife.org
- Design survey/interview questions
- Review language & criteria for consumer-focused outreach and education programs (Impact Awards)
- Create tools for encouraging and supporting meaningful engagement
 - Statement on the Value of Consumer Engagement
 - Bringing Your Voice to the Table: Maximizing the Individual and Family Perspective in the Regional Genetics Collaboratives

Assessing Consumer Needs

- *2013 Survey on Access to Care for Individuals with Genetic Conditions*

Romelczyk, Homan, Telfair, Dave, Keehn, Maiese, NCC Evaluation Workgroup. **Healthcare Coordination and Transition for Individuals with Genetic Conditions.** Maternal and Child Health Journal, 2015.

- *2015 Follow-Up*
 - *What are the barriers to care/access? What should be improved?*

Assessing Consumer Needs, cont.

- *Survey on Genetics Services: Resources, Referral, and Collaboration, April 2014*
 - Questions/requests for info about genetic services
 - Sources for trusted information on genetic services
 - Barriers that prevent access to genetic services
 - Need for additional educational resources
- *Understanding the Needs and Experiences of Pediatric Patients with Genetic Conditions, spring 2014*
 - Most/least helpful sources of advice
 - Problems parents had to figure out on their own
 - Most difficult times to find services for child
 - Advice for healthcare providers
 - Recommendations for other parents

Assessing Consumer Needs, cont.

- *Survey on RC Consumer Engagement, fall 2014*
 - Level of consumer engagement, types of activities
 - Suggestions/changes for improving consumer engagement in the regions
 - Training/mentoring in the regions
 - Satisfaction with addressing consumer needs
 - Diversity
- *Visioning Session, winter 2015*
 - What will genetic services look like?
 - What gaps in access will families face?
 - How will we look to bridge those gaps?

Building Upon Successful Strategies: Impact Awards



1. Center for Jewish Genetics
2. Gallaudet University
3. The Hali Project
4. Boston University School of Public Health
5. Michigan Public Health Institute
6. Nemours A.I. Dupont Hospital for Children
7. University of Wisconsin Madison

IMPACT

IMPACT

IMPACT

Next Steps

- 2015 Follow Up Survey on Access to Care= longitudinal data on access to care
- Orientation guide for consumers
- NGECCN Consumer Advisory Group Listserv
 - More diverse perspectives (RCs, LENDs, Title V, Family Voices, P2P, etc.)
 - Facilitate dialogue around consumer needs, gaps, and how the Regional Care Centers can better address those

Next Steps, cont.

- Assess key “transition” points where additional patient and provider education is needed
- Continue providing/creating family-friendly resources that help individuals understand and access genetic services and support
 - GenesInLife.org
 - DiseaseInfoSearch.org
 - Advocacy ATLAS
 - Free print/electronic materials:
geneticalliance.org/publications/order

Thank You!

The activities of the NGEEN are funded by the Health Resources and Services Administration (HRSA), Grant no. U22MC04100, National Coordinating Center for the Regional Genetic Services Collaboratives, total award amt. \$1,300,000.

Sharon Romelczyk, MPA, Program Manager

National Genetics Education and
Consumer Network

Genetic Alliance

sromelczyk@geneticalliance.org

202-966-5557 x 203

